Canadian Hemophilia Society
Help Stop the Bleeding
Société canadienne de l'hémophilie
Arrêtons l'hémorragie

Submission to the Canadian Agency for Drugs and Technologies in Health (CADTH) by the Canadian Hemophilia Society on fidanacogene elaparvovec

Name of drug	**fidanacogene elaparvovec**
Indication	**Hemophilia B**
Name of the patient group	**Canadian Hemophilia Society (CHS)**
Author of the submission	**David Page with input and review from members of the CHS Blood Safety and Supply Committee**
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1. About our patient group

Founded in 1953, the Canadian Hemophilia Society (CHS) is a national voluntary health charity. Its mission is to advocate to improve the health and quality of life for all people in Canada living with inherited bleeding disorder until cures are universally available. Its vision is a world free from the pain and suffering of inherited bleeding disorders.

The Canadian Hemophilia Society, whose **national headquarters** are in Montreal, is an organization that works at three levels: nationally, provincially and locally. We have **ten provincial chapters** across the country. Some of our chapters have additional local structures that we refer to as regions.

Its **Board of Directors** is made up of individuals with valuable skills and representing the organization's ten provincial chapters. Each provincial chapter in turn is managed by its own Board of Directors. Many chapters are separately incorporated and have their own charitable registrations. Three provinces—**Québec**, **Ontario** and **Manitoba**—currently have offices with permanent staff. All chapters work in accordance with **CHS by-law** and conform to national policies. The national organization and its ten chapters share a common vision and mission. The CHS has approximately 300 active volunteers across the country.

The CHS is affiliated with the **World Federation of Hemophilia** which is officially recognized by the World Health Organization. We work in collaboration with health care providers in Canada's 26 inherited bleeding disorder **comprehensive care treatment centres**, the blood system operators (Canadian Blood Services and Héma-Québec), the Network of Rare Blood Disorder Organizations, the rare disease community, and others who share our common interests.

Charitable Registration: 11883 3094 RR 0001

Website: **www.hemophilia.ca**

2. Information gathering

The CHS gathers information on the patient perspective in a number of ways.

The CHS Blood Safety and Supply Committee (BSSC) is made up of a dozen patients, physicians and nurses. Meeting monthly, their role is to inform and advise the Board of Directors and the community on key issues pertaining to the safety, efficacy and availability of coagulation therapies for inherited bleeding disorders. Collectively, they have over 200 years of experience in this field. Members of the BSSC attended the latest Congresses of the International Society of Hemostasis and Thrombosis (Montréal, June 24-28, 2023) and the World Federation of Hemophilia (Montréal, May 8-11, 2022), where the latest research on novel therapies was presented.

Gene therapies for hemophilia B have been in clinical trials for more than ten years. The CHS and its BSSC have closely followed the results of this research by attending medical conferences where results are presented, and reading peer-reviewed journal publications. Every two years, the CHS, in collaboration with the Association of Hemophilia Clinic Directors of Canada, organizes a three-day medical/scientific symposium where the latest research is presented and discussed. People with hemophilia B from Canada and abroad who have received gene therapy in clinical trials have presented their experience at these meetings. The latest symposium was held May 4-7, 2023. A session, entitled **GENE THERAPY: MANAGING EXPECTATIONS** was dedicated to gene therapy, including patient perspectives, and can be viewed at …

https://youtu.be/rDumGahug-Y
“Hemophilia gene therapies: the current state of affairs”
Presented by DR. DAVID LILLICRAP, Kingston General Hospital, Ontario

https://youtu.be/onc1WwIZdmY
"Why I said 'Yes' to gene therapy"
Presented by LUKE PEMBROKE, Greenwich, England, United Kingdom

https://youtu.be/HJv53a31gXQ
"Why I said 'No' to gene therapy"
Presented by RICK WAINES, Victoria, British Columbia

https://youtu.be/J1-tpIIqIHI
“Updates on hemophilia gene therapies clinical trials in Canada”
Presented by DR. ALFONSO IORIO, Hamilton Health Sciences Centre, Ontario

https://youtu.be/CT4VYCGdY5I
“Hemophilia gene therapies roll-out: are HTCs ready?”
Presented by DR. ROY KHALIFÉ, The Ottawa Hospital, Ontario, and
DR. JERRY TEITEL, St. Michael’s Hospital, Toronto, Ontario

https://youtu.be/W5lxTsJ3gjY
Open discussion with panel
Moderator: DR. ROY KHALIFÉ, AHCDC
Panelists: DR. ALFONSO IORIO, DR. DAVID LILLICRAP, DAVID PAGE, LUKE PEMBROKE, MARK SKINNER, DR. JERRY TEITEL, RICK WAINES

The CHS is in regular contact with its members through chapter meetings where current and future therapies of all types are discussed. In addition, members of the BSSC are in regular contact with their counterparts in hemophilia patient organizations around the world and the BSSC is represented on the World Federation of Hemophilia’s Coagulation Products Safety, Supply and Access Committee.

To collect specific perspectives from patients and caregivers with hemophilia B on the burden of disease and treatment, satisfaction with current treatment and the improvements people would like to see in a new treatment, the CHS in conducting an online survey launched on July 10, 2023. The survey was publicized via different CHS and chapter communication tools, including the CHS website, e-mail, Facebook, Twitter and Instagram. The questions asked are identical to those in the CADTH patient input template. We have received 17 responses up to July 31, 2023. All respondents are affected by severe or moderately severe hemophilia B without inhibitors. The results of that survey are presented in SECTIONS 3, 4, and 5.

In addition, in September 2022, the CHS conducted an online survey of Canadians with severe hemophilia A and B to learn their hopes and expectations for gene therapy and received 39 responses. The results of that study are presented in SECTION 5.

3. Disease experience

Joint damage, primarily to knees, ankles and elbows, caused by repeated internal hemarthroses, is the primary physical health impact of hemophilia B. Bleeding can be caused by very minor trauma. These impacts are clearly reflected in the survey results.

Overall quality of life

- *Reduction in quality of life. Constant worry about injuries and bleeding, and the long recovery time. Twice-weekly treatments.*
- *The exclusion from certain activities is a real factor in mental health. As an adult, not being able to participate in household duties, the chronic pain, knowing that I will have even more limitations in the future, not being able to contribute to savings for later invalidity, the worry that I will be a burden on loved ones; all these weigh on me.*

The need to refrain from physical activities and sports

- *As an adult, hemophilia has a big impact on my daily life. Many activities are chosen relative to my condition. I try to limit the risk of injuries. Even my career choice was affected by hemophilia.*
- *My son has severe hemophilia B. There are certain activities he has to be careful doing or can't do at all. A small injury can easily become a trip to the hospital and weeks of recovery.*
- *I take caution re activities, even benign sports.*
- *There is constant worry that when a trauma happens there will be a delay in treatment and life-threatening response times.*
- *We must make careful decisions about activities that come into play now that he is older.*

Reduced mobility

- *My mobility, strength and endurance are significantly impacted on a daily basis.*
- *I have joint pain and stiffness in knees and ankle that make walking painful and joint pain and stiffness in elbows that limit certain functions.*
- *He is now too heavy for us to carry if he has a bleed that affects his walking. We have a wheelchair for him for these instances.*
- *My joints are affected. Lots of pain, every day. I've had lots of surgeries and can't function normally.*

Joint replacements

- *I have had several joint replacements and severe back pain due to the hemophilia.*
- *I have had two knee replacements in the last five years.*

4. Experiences with currently available treatments

The only currently approved products for the treatment of hemophilia B are clotting factor concentrates containing factor IX. Treatment for severe and moderately severe phenotypes of hemophilia B is for the vast majority of patients by regular prophylactic (preventative) intravenous infusions (IV), usually administered at home. Both recombinant and plasma-derived formulations are available in Canada. Recombinant forms can be either "standard half-life" preparations which require two to three IV infusions per week or "extended half-life" preparations, usually requiring only one infusion per week.

These treatments are prescribed through the Canadian network of 26 hemophilia treatment centres and are available at no direct cost to the patient through the Canadian Blood Services Plasma Protein and Alternative Products Formulary. Typically, patients/caregivers go to the treatment centre or hospital blood bank every one or two months to replenish their home inventory. In addition, they have more in-depth assessments by the interdisciplinary care team once or twice per year.

No alternatives to IV factor IX are currently approved. This is unlike hemophilia A where monoclonal antibodies (emicizumab) mimicking the function of factor VIII and injected subcutaneously are in widespread use. Subcutaneous non-factor IX replacement therapies to treat hemophilia B are in clinical trials. These include anti-tissue factor pathway inhibitors such as concizumab (licensed in Canada for those with inhibitors to factor IX) and marstacimab, anti-antithrombin therapies such as fitusiran, and anti-protein C therapies. It is difficult to predict if and when these products will get marketing approvals in Canada. See **www.hemophilia.ca/products-in-the-pipeline**.

Early initiation of prophylaxis provides continued protection against joint damage throughout childhood compared with delayed initiation, but early prophylaxis is not sufficient to fully prevent damage. At the exit of the landmark Joint Outcome Continuation Study in hemophilia A, MRI osteochondral damage was found in 77% of those on secondary prophylaxis and 35% of those on primary prophylaxis. (Beth Boulden Warren, Marilyn J. Manco-Johnson et al. **https://doi.org/10.1182/bloodadvances.2019001311**, Blood Adv (2020) 4 (11): 2451–2459.)

While joint health research on hemophilia B lags behind that of hemophilia A because of the smaller numbers affected, there is little reason to believe that results are different. As long as factor levels fall below 10-15%, as is inevitable with factor replacement therapy, joint damage will occur in the long term. Only maintenance of higher levels will avoid this. **I. E. M. Den UIJL**, **E. P. MAUSER BUNSCHOTEN**, **G. ROOSENDAAL**, **R. E. G. SCHUTGENS**, **D. H. BIESMA**, **D. E. GROBBEE**, **K. FISCHER** **https://doi.org/10.1111/j.1365-2516.2011.02539.x**

This is how the 17 respondents to the recent survey rated their satisfaction with current treatments.

- Very satisfied 4
- Satisfied 7
- Neither satisfied nor dissatisfied 5
- Dissatisfied 0
- Very dissatisfied 1

Patients and caregivers described their current treatments.

Safety and efficacy

- *Current factor concentrates protect well against most bleeding. I have approximately 2 to 3 joint bleeds per year despite prophylaxis.*
- *While receiving his factor, my son is can run around like a normal kid, with minimal bleeds.*
- *The support and care we get at the_____ Children's Hospital are excellent. They are very knowledgeable and willing to help. I just wish my son didn't need to have so many needles all the time.*
- *Bleeds seem to be controlled. We are very careful so this could be because of our efforts.*
- *The concentrates are reasonably effective in protecting against bleeding.*
- *With the EHL products, he doesn't bruise as easily now and has 1 or 2 minor bleeds per year, commonly in his ankle. No side effects or inhibitors.*
- *Our current long-acting clotting factor works great. It is easy to use and infuse; however, so many pokes (IV infusions) every single year can be traumatic.*
- *The current treatment regime had to be adjusted to be given within a shorter time line as additional bleeds were happening.*
- *We recently changed from an SHL product to an EHL. The number of treatments went from three times a week to one. That is a huge plus. Both medications have worked well.*
- *We use an EHL FIX once a week through IV infusion. This is usually enough factor for him to get through a 7-day period without any bleeds. On this prophylaxis schedule, generally in one year we may need to take him to the Children's Hospital 1-2 times per year to treat a bleed.*
- *He has missed some school with bleeds to improve healing.*
- *The factor IX only lasts 24 hours in the bloodstream so if you have. A major trauma it means several days of infusions.*

The burden of treatments

- *The treatments, even if they're just IV infusions, greatly complicate everyday life, travel, and leisure activities.*
- *Infusions can be difficult because the success of the needle getting in the vein is dependent on his vein visibility at the time of injection. A side effect would be that over the years he has complained about pain at the injection sites of his hands.*
- *It is super hard and I have always been hard to infuse.*
- *Injection sites are scarred.*
- *An IV infusion every 5 days. I manage despite poor veins.*
- *He has to have needles for factor replacement every week, and blood tests way more often than any other kid. A small injury can easily become a trip to the hospital and weeks of recovery. Then he gets more needles to add more factor IX to his blood to try to speed up his recovery.*
- *Regular treatments are only a slight nuisance.*
- *I get frequent phone calls from school due to cautious staff members not familiar with this disorder.*
- *I give him weekly infusions, or more if injured, through a port.*
- *The side effects are with my veins. I feel them getting used up. They are more and more discoloured. The aesthetic aspect bothers me.*

Socioeconomic aspects

- *There are a fair amount of trips to the clinic, so time off work for parents.*
- *The clinic visits and follow-up are seemingly more difficult to access and professional staff positions are not always filled.*
- *The difficulties in accessing treatment are mostly time off work if something happens and we need to take him to the hospital. We live fairly close to the _____ Children's Hospital. One of the reasons we live where we do is because of the access to the hospital.*
- *Travel and insurance are an issue.*
- *I take time off work to take my son to appointments. He needs frequent blood tests. He has pain at injection sites. Going to ER when clinic is closed is often a bad experience. Parking costs at hospitals are super high.*
- *I have 6-8 clinic visits per year to pick up concentrates and have blood tests. I have to miss work.*

5. Improved outcomes

In September 2022, the CHS conducted an online survey of Canadians with severe hemophilia A and B to learn their hopes and expectations for gene therapy and received 39 responses. The survey, whose answers were anonymous, was targeted at Canadian residents with severe hemophilia A or B, fourteen years of age or older, who represent the patient group that might consider taking gene therapy in the next five years.

The survey was publicized via the usual via CHS communication channels: website, Facebook, Twitter, and certain chapters' social media, and was available in both English and French.

Thirty-nine people completed the survey, 31 with hemophilia A, seven with hemophilia B and one not specified. This accurately reflects the prevalence of severe hemophilia A and B in the population.

Fifty-four percent (54%) indicated they thought they would be eligible for gene therapy, 28% thought they would not be eligible and 18% said they didn't know. Reasons for thinking themselves to be ineligible include a past history of inhibitors, pre-existing antibodies to the AAV vector used to deliver the gene for factor VIII or IX, age (under 18 or over 75) and other medical conditions, for example, active liver disease.

Respondents were asked the minimum level of factor VIII or IX expression predicted to be achieved that would make them want to have gene therapy. Answers varied widely, but 60% hoped for sustained expression of 30% or more.

Table 1: Minimum factor VIII or IX expression desired

Minimum factor VIII or IX level desired (normal is 50-150%)	% of respondents
5-10%	7%
10-20%	17%
20-30%	7%
30-40%	17%
40-100%	43%
I don't know	10%

Respondents were also asked how long they would expect the factor level they chose in the question above to last for them to accept gene therapy. Again, answers varied widely, which is not surprising given that clinical trials for hemophilia gene therapy have given no clear answer to this question. It is worth noting that more than 6 out of 10 respondents (63%) indicated they expected gene therapy to be effective in preventing bleeding for at least 10 years.

Table 2: How long desired factor level should last to be acceptable

Time that gene therapy will be effective	% of respondents
My whole life	40%
More than 10 years	23%
5-10 years	10%
3-5 years	3%

Time that gene therapy will be effective	% of respondents
Less than 3 years	7%
I don't know	17%

Respondents were asked how much certainty they needed as to the factor VIII or IX level they might achieve. More than half (56%) need to be *quite sure* or *absolutely sure* of the eventual factor level obtained. Unfortunately, clinical trial results, especially in hemophilia A, show a highly variable and unpredictable level of response from individual to individual, ranging from no response at all to levels above normal.

Table 3: Level of certainty needed regarding level and duration of factor expression

I need to be absolutely sure of the factor VIII or IX level I will get.	13%
I need to be quite sure of the factor VIII or IX level I will get.	43%
I am ready to accept some uncertainty.	20%
I realize my factor VIII or IX level could be much lower or higher than expected and I am ready to take a chance.	17%
I don't know.	7%

Respondents were asked if they would accept gene therapy if they were told in advance that steroids would probably be needed in the period following administration. Thirty-eight percent (38%) said yes, 21% said no and 41% didn't know. Many respondents commented that this was an important factor that would cause them to pause. Many others indicated they needed more information on this subject.

The survey asked if people would accept to receive gene therapy knowing that that there would be frequent blood draws in the weeks and months following administration, and they would need to be followed up in a registry for 10 to 20 years. Sixty-six percent (66%) answered yes, 10% answered no and 24% didn't know.

Respondents were asked to express their overall attitude to gene therapy. (More than one answer was allowed.)

Table 4: Overall attitudes to gene therapy

I am very interested in receiving gene therapy.	45%
I am not interested in receiving gene therapy at this time.	14%
I am concerned about short-term side effects.	35%
I am concerned about long-term side effects.	52%
I am concerned that FVIII or IX levels will not be high enough to prevent bleeding.	44%
I am concerned that FVIII or IX levels will not last long enough.	55%
I am waiting for more information.	48%
I intend to wait for future generations of gene therapy.	31%
I am ready to take a chance.	10%
I am not ready to take a chance.	28%

We asked respondents to indicate how knowledgeable they felt themselves to be.

Table 5: Level of knowledge about gene therapy

Very knowledgeable	13%
Quite knowledgeable	16%
Somewhat knowledgeable	38%
Not very knowledgeable	29%
Not knowledgeable at all	3%

Respondents also indicated what they would like to know more about. Answers were:

- *Everything.*
- *Nothing. I just wouldn't do it.*
- *Nothing, I trust the science. I just want it.*
- *How the therapy can be improved to provide better and more consistent results.*
- *How to avoid the exclusion of those with HIV and/or HCV infection.*
- *The complete working of it.*
- *The experiences of those who have gone through the process.*
- *Why and how it lasts for the amount of time that it does.*
- *More about side effects.*
- *If additional doses are possible if my levels drop, especially with future generations of gene therapy.*
- *How it's being developed safely and securely.*
- *Side effects, long term effectiveness.*
- *Parallel information from other gene therapies for other disorders.*
- *Trough levels, duration of levels, risks.*
- *Cognitive/neurological risks.*
- *Risks of comorbidities.*
- *Will government be inclined to pay for gene therapy?*
- *The kinds of support that would be available to a person in the first few weeks and months when there are numerous blood draws and appointments with medical personnel.*
- *The lasting effects for those who went through clinical trials and received corticosteroids.*
- *If I don’t respond, can I go back to my previous treatment with factor?*
- *The long-term risks.*

Patients and caregivers with hemophilia B, via the July 2023 survey undertaken for the review of fidanacogene elaparvovec, told us this about how gene therapy could potentially change their lives.

- *How can it not? Nothing beats even a year of no infusions or bleeds.*
- *Gene therapy would transform my life. I wouldn’t bleed. People who don’t have hemophilia cannot imagine the pain of a joint bleed; they have no idea.*
- *I could imagine it being quite fantastic. Minimal needles, less stress and hopefully even fewer bleeds.*

- *Gene therapy could revolutionize my daily functioning. It could optimize my current health state and improve my quality of life by reducing the amount of time and energy expended on treatments and preventing bleeding episodes.*
- *Gene therapy would be life-changing for my son. He would go from having 52-75 needle pokes per year to only needing 2-5 needles with gene therapy. If his factor IX levels are consistently high from gene therapy, he can participate in activities that his doctors told us he can't because of physical contact. He tells me he always has to be aware of what dangers there are, even if they are minor. Something as minor as a hit with a ball or a bump against the wall can cause a bleed. Gene therapy could take some of his worries away if he doesn't have as high of a chance of a bleed. He wouldn't have bruises all over his body all the time. We would also have less trips to the hospital.*
- *Confidence to travel and do physical work.*
- *Less restrictions on activities. No weekly prophylaxis. No medications needed. A sense of safety knowing he has factors at all times in his body.*
- *No more traumatic needles weekly. No more worry of injury response time. Ability to go out and take trips longer than a week without worry.*
- *Gene therapy is a game changer. Going into teenage/adulthood, gene therapy would be huge for mental health and him feeling more "normal" and being able to enjoy life more fully.*
- *Gene therapy has the potential to keep my factor IX at a level that would be very effective in preventing bleeding (i.e. 30-40%). I would no longer need IV infusions, except for surgeries or serious trauma.*
- *Gene therapy would help my son dramatically without the fear of constant injuries. Mentally, removing his phobia around needles would improve his lifestyle incredibly.*
- *I could travel more easily. Now, I limit my travel because of the difficulty of carrying bulky medication. Without 2 to 3 infusions per week, I'd have more time for my family and to do activities that improve my quality of life.*
- *It would make the last years of my life so much easier.*

6. Experience with drug under review

A small number (likely close to five) Canadians have undergone gene therapy for hemophilia B, but nothing is known to CHS about their experience outside the preliminary data for the full trials.

In early 2023, with the approach of gene therapies to the Canadian market, the Canadian Hemophilia Society produced *All About Hemophilia Gene Therapy, A guide for patients and caregivers* (**bit.ly/AllAboutHemophiliaGeneTherapy**).

This is an excerpt from the introduction to the booklet.

> *The hemophilia community has been waiting for gene therapy for years. Many have hoped it would be a cure. In the past few years, we have started to see promising results from the late stages of clinical trials for gene therapy in both hemophilia A and B.*
>
> *With these results, however, we have learned that the reality of gene therapy differs from original hopes and expectations. The gene therapies that will be made available are promising new treatment options but are not full cures and are not for everyone.*
>
> *Gene therapy is very different from the prophylaxis therapies we are used to. It is a one-time treatment that cannot be taken back and cannot be repeated. And we have also learned that we have a lot of work to do to ensure its safe and optimal introduction as a treatment option.*
>
> *People with hemophilia (PwH) and their families must have all the information they need to make a fully informed decision as to whether or not to consider gene therapy.*
>
> *PwH benefit from a number of therapeutic options, many of which have a long track record of safety and efficacy. Therefore, the benefits and risks of gene therapy must be seen in comparison to current treatments.*
>
> *Ten key considerations that will be explored in this booklet include:*
>
> 1. *Gene therapy is not for everyone.*
> 2. *Many people are not eligible.*
> 3. *Predicting the outcome of gene therapy for an individual is not possible; however, for some, it can result in a significant improvement in quality of life.*
> 4. *Gene therapies for hemophilia A and B are different.*
> 5. *Decisions on moving ahead with gene therapy should be made only after a rigorous process of informed, shared decision-making.*
> 6. *Recipients of gene therapy must be ready for frequent blood draws and hospital visits in the first months after administration.*
> 7. *Most of those with hemophilia A and some with hemophilia B will require treatment with corticosteroids for up to many months after administration of gene therapy. These drugs can have significant side effects.*
> 8. *Reduction in consumption of alcohol may be recommended after gene therapy.*
> 9. *Clinicians monitoring people after gene therapy must be supported by a network of experienced experts.*
> 10. *All recipients of gene therapy must be enrolled in a registry. This registry will follow people for life.*

7. Companion diagnostic test

Testing for antibodies to the AAV-5 vector is required before undergoing gene therapy. With regard to fidanacogene elaparvovec, those who test positive are deemed ineligible. Those who undergo gene therapy are required to have liver enzyme testing one to two times a week in the weeks and months following administration. A process needs to be in place to do the blood draws and send them to a laboratory for immediate analysis. Results must be analyzed very rapidly. Experts in hemophilia gene therapy must be available to advise physicians who are less experienced on when to initiate steroid treatment. Time is of the essence. If a rise in ALTs indicates a possible rejection of the vector, a course of steroids is started immediately and lasts for several months. A failure to act quickly can mean that expression of factor IX is permanently diminished or entirely eliminated. Side effects of the steroids, affecting both physical and mental health, can be significant. Patients and their families need to be adequately counselled regarding the potential need for steroids and their health impacts well in advance of any decision to receive gene therapy.

8. Anything else?

In the absence of peer-reviewed publications describing the results of Phase III clinical trials for fidanacogene elaparvovec, the CHS is unable to comment on the relative benefits and risks compared to current therapies or other gene therapies for hemophilia B currently under review by Health Canada.

APPENDIX: Patient group conflict of interest declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. **Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.**

   The CHS received no help from outside our patient group to complete the submission.

2. **Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.**

   The CHS received no help from outside our patient group to collect or analyze data used in this submission.

3. **List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.**

   Table 1: Financial Disclosures

COMPANY	*Check appropriate dollar range*			
	$0 to 5,000	$5,001 to 10,000	$10,001 to $50,000	In excess of $50,000
Bayer				X
BioMarin		X		
CSL Behring				X
Novo Nordisk				X
Pfizer				X
Roche				X
Sanofi				X
Takeda				X

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name: **Sarah Ford**
Position: **Chief Executive Officer**
Patient group: **Canadian Hemophilia Society**
Date: **August 10, 2023**